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REVIEW

Review: a conceptual model of perceived burden of informal caregivers for older persons with a severe functional psychiatric syndrome and concomitant problematic behaviour

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Aims and objectives. This literature review aims to delineate the determinants of perceived burden by informal caregivers and provide insight into the interrelatedness between these determinants.

Background. Despite the attention given to the various determinants of perceived burden, their interrelatedness has not been unravelled. Insight into this interrelatedness is mandatory for the development of successful, complex, multivariate interventions to reduce perceived burden of informal caregivers.

Design. Systematic review.

Method. Four electronic databases, CINAHL, Embase psychiatry, Medline, Psychinfo and reference lists of selected articles, were searched. Publications between January 1985–2008 were included if they concerned mental illness, burden and care giving. Articles were selected according to predefined inclusion and exclusion criteria.

Results. The results of mostly descriptive, cross-sectional and univariate research and the more process-oriented results coming from qualitative burden research are organised in a process orientated conceptual scheme or model adapted from the stress-theoretical framework by Lazarus and Folkman. The model indicates that perceived burden must be understood through the individual appraisal of stressors and the availability and use of internal and external resources. Perceived burden is the outcome of multiple, clinically overlapping psychiatric problems, problematic behaviour and functional disabilities.

Conclusions. So far, intervention programs to reduce perceived burden of informal caregivers have not devoted much attention to the interrelatedness of the origins of burden. The conceptual model provides an overview of the various determinants of perceived burden and a clear picture of the possible interrelatedness appears. This overview of the most important sources of burden helps to develop a complex, multivariate intervention that is comprehensive, long-term, individually tailored and has the flexibility to meet the dynamics of burden over time.

Relevance to clinical practice. Use of the conceptual model is crucial to professional nursing and the quality of support of informal caregivers.

Key words: burden, caregiver, older, mental illness, nurses, nursing

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Introduction

During the past decades, the policy of deinstitutionalisation of psychiatric patients has resulted in increasing numbers of people with severe mental illness living in the community. Among them are also older people, who rely on informal caregivers for support in daily living (Ministry of Health, Welfare and Sport 2001, Muhlbauer 2002, Rose *et al.* 2002).

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As family members are the most important informal caregivers, the role of family has become more important. However, the availability of informal caregivers is decreasing (Bosanquet 2001, Struijs 2006) because of the increased participation of women in the workforce, increased geographical distance between family members and a smaller number of children per family (Struijs 2006). Caring for the caregivers is therefore an important issue in community care, especially in care situations that are long lasting, where behaviour of the care receiver is problematic and the situation seems to be without any prospect of improvement. Typical examples of such situations are when the psychiatric illnesses are accompanied by a high prevalence of acute and chronic somatic illnesses and adverse effects of medication. They imply increments in care that go beyond the boundaries of normal or usual informal care (Montgomery *et al.* 1985, Biegel *et al.* 1991, Magliano *et al.* 1996, Sisk 2000). For caregivers, it means a significant investment of time and energy over extended periods of time, involving tasks that may be unpleasant and uncomfortable (Biegel *et al.* 1991). Stress is chronic and enduring, and the caregiver is often an older person (de Boer 2005). The complexity of care, the increasing appeal to informal caregivers and their decreasing availability place caregivers at risk of becoming overloaded and stressed (Ohaeri 2003).

In this review, we studied the literature for factors or determinants that may influence, or be related to, the amount of stress in informal caregivers of older people with psychiatric problems and with problematic or unpredictable behaviour. Factors related to perceived burden are organised and categorised in accordance with the frame of the stress-theoretical model of Lazarus and Folkman (1984). Insight into the origins of the informal caregivers' perceived burden, facilitates the development of a complex, multivariate intervention that is comprehensive, long-term and individually tailored with the flexibility needed to meet the dynamics of burden over time (Biegel & Schulz 1999, Sörensen & Pinquart 2003, van Meijel *et al.* 2004, Schultz *et al.* 2005).

Method

Selection of the articles

Potentially relevant research articles published from January 1985–2008 were retrieved from four databases: CINAHL, Embase psychiatry, Medline and Psychinfo. First, the databases were searched using the following keywords: (mental disorder OR mental disease OR mental illness) and (caregiver OR support OR family) and (burden) not (cancer) not (dementia OR Alzheimer). The retrieved articles were screened for their relevance, based on the title and abstract. Bibliographies were subsequently searched for potentially relevant articles not yet retrieved. The remaining articles were read and screened to determine whether they met the following inclusion criteria; informal caregivers of older people and adults with a (major) depression, a bi-polar disorder, an anxiety disorder, schizophrenia, obsessive compulsive disorder, personality disorders and concomitant difficult behaviour, originally published in English or Dutch. Studies focusing mainly on informal caregivers of people with dementia, delirium, or other cognitive syndromes, a physical disease, or research carried out in non-western countries, intervention studies and validation studies were excluded. The literature reviewed included papers reporting both qualitative and quantitative research, reviews and government reports. Articles included had to report at least the type of research, search strategy, instruments used, heterogeneity or homogeneity of informal caregivers and identified determinants. All studies making up the foundation of this systematic review were read repeatedly. The findings from these studies were then summarised in tables (Tables 1 and 2), and the result of this systematic review is a synthesis of these analyses.

Building the conceptual model

Perceived burden is the result of the magnitude of the stressors, balanced by the way informal caregivers are able to make use of internal and external resources (Chappell & Reid 2002). Informal caregivers give meaning to and respond to the experience of caring for someone with a mental illness. The process of adapting to and making sense of the situation that they find themselves in, evolves and changes in relation to resources and health outcomes.

Despite the attention paid to the various determinants of perceived burden in previous research, the potential moderating or mediating influence of the whole set of determinants of perceived burden has not yet been addressed. Ignoring the potential interrelatedness of the determinants of perceived burden may therefore lead to biased conclusions. To address this issue, we applied a process-oriented model based on the stress-theoretical model of Lazarus and Folkman (1984). This model helps to organise findings of the literature search concerning the determinants related to perceived burden into three interrelated major components: (1) the stressors in the actual situation, (2) the process of how these stressors evolve and change in relation to the use of internal and external resources and (3) the research results related to outcomes such as perceived burden itself and various health consequences.

Table 1 Overview quantitative research

Study	Design	Research question	Sample	Variables	Results
Pearlin *et al.* 1981	Longitudinal	Examine the various aspects of the three major components of stress; its sources, mediators and outcomes	IC 1106 Age 18–65	Chronic life strains; Job disruption Indicator of stress; Depression Self-concepts; self-esteem Coping Social supports The process of stress Economic strain Mastery Self-made instrument called LISREL	Internal resources Exacerbated stresses can erode positive concepts of self. The diminished self-concepts leave one vulnerable to experience symptoms of stress, like depression. Intervention of coping and social support are mainly indirect. They do not directly buffer depression; they minimise the development of depression by dampening the antecedent processes such as lowering of self-esteem and mastery change
Thompson & Doll 1982	Cross-sectional	Examine the emotional and social costs of families charged with the burden of care giving for their mentally ill kin	IC 125 Age 51 Length six months or over	Subjective burden = emotional costs; Freeman and Simmons (1961) index of family members and a modified form of Incompetence Sentence Blank by Potter and William (1947) Objective burden = financial burden, role strains, interruptions of normal life, supervision, problems with neighbours	Stressor Providing supervision otherwise unnecessary Neglect of responsibilities to other family members Financial burden, disruption of normal life Disruption of social life because of the pt. behaviour and presence including neighbours Outcome Embarrassment, coping with chronic feelings of being overloaded, feelings of being trapped, anger and intense resentment and bitterness. One of four pt were physically accepted but emotionally isolated by relatives SB and OB share variance but seem to be aroused by different factors
Montgomery *et al.* 1985	Cross-sectional	Examine the relationships between care-giving experience and SB/OB	IC: 80 Age 56 Diagnosis acute need of care	Demographic data OB: self-developed SB: 13 item adapted from Zarit's scale Care giving; developed a list of 21 tasks	Stressor OB and SB share 12% of the variance OB is caused by nursing care, bathing and dressing, walking, transport and errands and the presence of other family members and not by characteristics of the caregiver or care SB is caused by characteristics of the caregiver; age and income, employment and by one type of task, namely bed and wheelchair transfer

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Noh & Turner 1987	Cross-sectional	Explore the relationship between level of chronic stress and the extent of psychological distress	IC 211 Age 45 Diagnosis S	Mental health GHQ Goldberg Subjective burden Pt as a problem Pasmanick Objective burden Personal Adjustment and role skill scale by Ellworth Mastery Scale by Pearlin and Schooler Social support Revised Kaplan Scale together with open-ended questions Stressful life events 21 item developed in Canada health survey Descriptive information Gender, age etc.	External resources Not social support and not life events but mastery is the only contributor to distress Primary consequences Subjective burden makes a contribution to psychological well-being Distress tends to increase with the length of time the pt has been in the community Symptomatology of the pt, sex and education contributes to the variability of GHQ scores
Noh & Avison 1988	Cross-sectional	Examine how experienced burden is affected by extent of psychiatric? Characteristics of pt and family structure and changes in the influence of life events and psychosocial resources on this perception differentiated for husbands and wives	IC 211 Age 45 Length 29 months Diagnosis S	Psychiatric factors: Brief Symptom Inventory (BSI) General Severity Index Community tenure = number of months at home Family environment Income Employment pt Children under 16 Stressful live events 21 item self-developed in a Canadian health survey Mastery Scale Pearlin and Schooler Social support The experience of being supported by others and Revised Kaplan Scale Family burden Nine-item pt as a problem scale by Pasmanick	Stressor Level of symptoms is the only psychiatric variable sign related to experience of burden for men and women Internal resources Men and women with low mastery scores are more likely to view their spouses as burdensome Life stress and mastery account for 14% variance of the burden Outcome Substantial variation in the extent of burden; men judge wives to be burdensome, which is strongly affected by other stressful life events The influence on perceived burden by children in the home, mastery, significant others, employment status vary by sex but none are statistically reliable

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Pearson *et al.* 1988 Older	Cross-sectional	Explore relationship between CB and patient status of cognitive status, functional status (IADL) and caregiver perceptions of clients' disruptive behaviour and distress regarding discrepancies between clients abilities and behaviours	IC: 46 Length two years or over Diagnosis D,A, hypomania	Cognitive status: MMSE Clients depression: Geriatric depression scale (Instrumental)Activity of daily living: Katz *et al.* ADL and IADL scale Disruptive behaviour: Mental status questionnaire (Deimling *et al.* 1984) Caregiver distress: asking to rate the degree of distress regarding the discrepancies between abilities and disabilities CB: Relatives Stress Scale (Green 1982)	Outcome Predictors of perceived burden: Pt functional status, disruptive behaviour, caregiver distress regarding abilities and behaviour, ADL limitations and sharing a household
Pruncho & Potashnik 1989	Longitudinal	Examine the impact of caregiving on the mental and physical health of spouse caregivers	IC 315 Age 70·1(45–94) Length 2·9 (one month–20·3 years) Diagnosis D	Questionnaire about health and behaviour of the older, physical and mental health of caregiver; self-developed Burden; Hopkins Symptom Checklist Depression; Center for Epidemiologic Studies Depression Index Affect balance scale (Bradburn)	Outcome Physical health; Caregivers report fewer visits to doctor than did general population Women caregivers over 65 rate their health as fair or poor more frequently than the general population. Caregivers over 65 rate higher rates of diabetes, arthritis, ulcers, anaemia than males and females in general population. Women 65 rate more hypertension and heart trouble Mental health: Caregivers over 65 more insomnia, more trembling, headaches, bad dreams, more nervous complaints, sleep problems. They use more psychotropic drugs, report more psychological distress and are more depressed than general population
Norbeck *et al.* 1991	Cross-sectional	Determine the unique and common support needs of family caregivers of child, adult and older psychiatric patients	IC 60 Age 50 (27–85) Diagnosis PDD, S, BD, Alzheimer	Current support needs based on current problems in life of CG, current support needs based on a case and five questions about support needs Modified Gottlieb interview protocol (1978)	External resources Support needs parallel the four general types; emotional, feedback, informational and instrumental For the categories under these support types, the specific support need was directly tied to the specific situation

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Hooker *et al.* 1992	Cross-sectional	Determine the association between neuroticism and optimism and mental and physical health outcomes. Test hypothesis that personality characteristics are related both directly and indirectly through perceived stress to mental and physical health	IC 51 Age 68·7 Length 4·6 years Diagnosis D	Personality: Neuroticism: Factor N of the NEO Five Factor Index, a short version (12 item) of the NEO Personality Inventory Life Orientation Test as a measure of dispositional optimism Perceived stress: Perceives stress Scale 14 item Mental health Center for Epidemiologic Studies Depression Index 20 item Bradburn Balance Scale 10 item Physical health Current Health Subscale of the Health Perceptions Questionnaire used in the RAND Insurance Study nine item Health index with the five most commonly used health questions in research Multilevel Assessment Instrument, a checklist of 20 chronic conditions	Internal resource Neuroticism and optimism are significantly related to mental and physical health outcomes Neuroticism directly affected all health outcomes and had indirect effect, through perceived stress, on mental outcomes. Optimism showed stronger indirect effects than direct effects on all health outcomes
Skaff & Pearlin 1992	Cross-sectional	Attempting to delineate the conceptual boundaries of loss of self and to identify the conditions leading to this occurrence	IC 527 Age 61·9 Diagnosis AD	Social and Socio-economic characteristics, engulfment, self-loss, competence and self-gain; self -developed scale from a larger set Self-esteem : nine items of 10 item Rosenberg scale Mastery: Mastery scale by Pearlin 1978 Depression: seven-item subscale of Hopkins checklist	Situation Loss of identity as a result of engulfment in the caregiver role is more common among spouses, females and younger caregivers. Surveillance and control, dangerous behaviour and amount of care giving predicts loss of self Process Loss of self and self-gain are not related to growth Limited social contact and lack of social roles other than the caregiving one is related to more loss of self Loss of self is related to self-esteem and mastery Mastery and self-esteem are predicted by social structural factors like income and education Outcome Greater depressive symptomatology

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Magliano *et al.* 1995	Cross-sectional	Describe coping strategies of key relatives of schizophrenic clients and explore their relationship with client and key relatives' sociodemographic characteristics, clinical status and key relatives SB	Informal caregivers: 31 Age 18–48 Length 6·3 Diagnosis S with clinical exacerbation of symptoms	Clinical status: Present State Examination Coping strategies: Family Coping questionnaire SB: Family Problems Questionnaire Sociodemographic characteristics; self-developed	Stressor Disorganised syndrome and psychomotor poverty lead to coercion Verbal aggression in IC is stimulated by pt behaviour, not by cognitive symptoms and in particular behaviour seen as intentional rather than as a result of the illness Coercion, avoidance, resignation were related to anxiety and depressive symptoms in key relatives Long duration is characterised by positive communication and social involvement of client
Mannion 1996	Cross-sectional	Exploring to better understand resilience and gratification among close relatives of people with mental illness	IC 18 Diagnosis BD D PS, SAD	Separate analyses of survey responses of spouses Family resilience Personal resilience Consumer resilience	External resource The contribution and sacrifices need to be validated and seen by children and other important persons Outcome Having a spouse with a mental illness can involve both burden and resilience. Personal resilience was more evident than the other two types
Solomon & Draine 1995	RCT	Testing hypothesis; greater degree of SB is related to greater severity of relative's illness, less availability of concrete social support and fewer coping resources of the IC	IC 225 Age 55·7 Length 12·7 Diagnosis S, AF	Sociodemographic factors and history of the mental illness and personal history Burden; an adaption interview Pai and Kapur combined with personal rating of the severity SB; by one-item self-rating scale Level of functioning scale = self-developed Social support; Norbeck Social Support scale Self-efficacy scale based on Hatfield Satisfaction with coping responses	Stressor Stressor variables like functioning ill relative, years of diagnosis, crisis yes/no, living with yes/no explains sign of SB Living with gives more perceived burden Internal resource Self-efficacy and mastery prevent high SB Satisfaction with coping is less SB External resources Social support mediators; greater support results in lower SB
Gallagher & Mechanic 1996	Cross-sectional	Examine the physical health of people living with a mentally ill person vs the physical health of the general population	IC no mentally household 716 IC mentally ill household 776 Age 45/48 Length 26% over five years Diagnosis S, MI and alcohol/drug, MI and physical condition	Health and functioning Self-report, physician visits, ADL Characteristics of mental illness Severity activity limitation, duration	Stressor Duration of illness is not supported Mentally ill men engage in more disruptive behaviour producing more distress, with negative health outcomes for the IC Being a child of a mentally ill person is more distressing than living with a MI person Outcome With a mentally ill person reporting more activity limitations and poorer health, increased physician visits

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Magliano *et al.* 1996	Cross-sectional	Explore the burden perceived by key relatives of OCD. Caregivers of patients with MD is control group	IC 32/26 Age 31·9/46·8 Length 6·5/9·9 Diagnosis OCD, control MD	Clinical status Present State Examination (PSE-9) and the Yale Brown OC Rating scale, Maudsley OC Inventory, Family Problems Questionnaire Sociodemographic characteristics: self-developed OB and SB by the PSE-9 section B; Assessment of disability and family burden	Stressor Family burden is not directly related to the specific mental disorder but instead to the severity of symptoms and the degree of client's social withdrawal Depressive feelings were more often found among the IC of OCD Outcome Moderate to severe OB correlated mainly to impairments in social functioning Moderate to severe SB correlated mainly to severity, being at one's beck and call, in need of rest OB and SB increasing with age Most frequent; nervous tension, worrying and irritability
Montgomery *et al.* 1985	Cross-sectional	Examine (1) the differences between key relatives and other relatives with regard to burden, choice of coping strategy, the presents of psychiatric symptoms (2) correlations between the coping strategies of the two types of IC and (3) influence of the coping strategies on the levels of perceived burden of the other relative	IC 90 Age around 50 Length 23 years Diagnosis S	Diagnose; PSE 10 Social disability of the pt; DAS OB, SB, support professionals, support social network, relatives' positive attitude to pt and criticism of pt behaviour; FPQ Positive communication, maintenance of social interests, coercion, avoidance, resignation, pt social involvement, use alcohol/drugs, collusive reaction pt; FCQ Behaviour and non-compliance, spiritual help, talking with friends, quality and frequency of social contacts, practical social support, emotional social support, presence of intimate friendship; SNQ	Internal resource Emotion-focused coping style spreading from one relative to another increasing the risk of a crisis Outcome The level of burden on other relatives does not differ from those on key relatives The risk of developing psychiatric symptoms is similar among all family members inclusive the ones without blood ties
Marsh *et al.* 1996	Cross-sectional	Explore a more balanced picture of the family experience concerning strengths – limitations and courage-despair and resilience-burden	IC 131 Age 20–81 mean 60·7 Length Diagnosis S, SAD, BD, MD, PD	Open-ended questions about: Personal qualities and strengths, Family qualities and strengths, Personal contributions Contributes of the relative Experienced gratifications Process of adaption of people Resources for positive changes	Internal resource Because of resilience, there is a need to expand the conception of the caregiver experience and not focus on burden alone. Services should be designed not only to reduce burden but also to maximise resilience

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Patterson *et al.* 1996	Cross-sectional	Present result of preliminary study of IC from older psychotic clients and describe features of schizophrenia that create unique stressors	IC 30 Age 59·8 (36–88) Length Diagnosis older with S, MD, SAD	Psychiatric symptoms: DSM-3-R pt version (SCIP-P) and Scale for the assessment of negative symptoms (SANS) and the scale for positive symptoms (SAPS), Problem behaviour: Pearlins 14-item scale of problematic behaviour and a four-point frequency scale ADL: Pearlin's 15-item scale of ADL and IADL Sense of loss: self-developed scale Role captivity: self-developed scale Stress moderators; Pearlin *et al.* 1990, Instrumental support en emotional support, Self-concept: self-esteem by 10-item Rosenberg Self-esteem scale and mastery by Pearlin *et al.* 1978, Coping: Ways of Coping questionnaire revised, Psychological symptoms: Brief Symptom Inventory and the Global Severity Index Physical health status: Interim Medical Survey	Situation Spouses provide more ADL assistance, report more personal and social losses, more loss of self, past and anticipated lifestyle. Overall spouses report higher levels of primary stressors Process High levels of emotional support, approach type of coping, less avoidance coping,. Spouses tended to report higher levels of mastery Outcome High levels of depression and anxiety. Spouses report a greater number of physical symptoms
Solomon & Draine 1996	Cross-sectional	Explain expressed grief	IC 225 Age 55·7 Diagnosis S, MAD	Social and? demographic characteristics, history of illness and personal history Grief; Texas Inventory of Grief A functioning scale self-made Behaviour; self-made Burden; Pai and Kapur scale Social Support; Norbeck Social Rating scale	Stressor OB and SB important factors in explaining grief Grief is ongoing because the IC is constantly adjusting to the new situation Living together for a long time results in less grief
Buck *et al.* 1997 Older	Longitudinal study	Investigate presence of psychiatric morbidity in informal caregivers	IC 623 home 129 long term care Age Length Diagnosis physical frail, mentally frail or both	Frailty = Physical frail 11 or more on the Clackmannan Disability Scale Mental frail = three or more on the Automated Geriatric Examination Computer Assisted Taxonomy Household structure, ADL, behavioural problems, formal and informal help, health and social services, social network, IF' health, demographic details; 30-item general health questionnaire to estimate the prevalence of psychosis, psychiatric illness	Outcome: Decline of psychological well-being, where age is not contributing to this result, the IC of mentally frail older are more depressed. Daughters and spouses were more likely to have higher GHQ results

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Fredman & Daly 1997	Cross-sectional	Evaluate weight change and caregiver stress	IC 200 Age 61 Length one year, daily basis Diagnosis; F, Stroke, rehabilitation like hip/knee fracture	Burden Interview Perceived Stress Scale Geriatric Depression scale	External resource Weight change related to: Lower level of education Poorer rated health More psychotropic drugs Pt more ADL limitations/stroke Weight change of 10 pounds is valid indicator of burden, stress, depression Coresidence more weight change
Jones 1997	Longitudinal	Compare family burden by the type of client–caregiver relationship	IC; (148 year 1, 135 year 2,143 year 3) Age; Parents 62, children ?, siblings?, spouses? Diagnosis; M illness	Caregiver Burden Instrument (Tessler)	Parental role Child role Sibling role Spousal role
Provencher & Mueser 1997	Cross-sectional	Investigate the relationships of perceived severity and responsibility attribution for positive and negative symptom behaviour to CB	IC: 70 Age 59·1 Diagnosis S, SAD	Characteristics of the participants; self-developed Severity of symptom behaviour : Behavioural Disturbance Scale Social Behaviour: The Social Behavioural Assessment Schedule Responsibility attribution for negative/positive symptom behaviour: The Responsibility Attribution Scale from Drown's Structure Attribution Questionnaire OB the Objective Burden Questionnaire SB The Subjective Burden Questionnaire	Stressor Positive symptom behaviour is related to SB Perceived Responsibility for Positive Symptom behaviour was not related to either OB or SB Outcome OB and SB are sign related Perceived less responsibility for Negative Symptom Behaviour report higher levels of OB independent of the severity of the symptoms

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Hill *et al.* 1998	Cross-sectional Additional qualitative data	Explore the perceived usefulness of professionals, quality of life, perceived needs in terms of providing services	IC 1113 Age 51 (15–92) Length 10 years (0–798 months) Diagnosis MD	Self-developed questionnaire Basic demographics Perceived usefulness of professionals Quality of life Perceived service needs	Internal resource One-third report negative changes in self-esteem and self-confidence, one-third report positive changes on both items and one-third report no change. Women more likely to have negative change External resources Friends social life only a small proportion reported a positive change. Family relationships almost equally balance between positive and negative impact Outcome Perceived service needs; 42% sought support for themselves as a result of the role of care giving. Suffering stress, anxiety, depression, own psychiatric hospital admission
Broe *et al.* 1999	Cross-sectional	To assess distress in a sample of caregivers who were selected from an Australian community survey rather than recruited via community – service agencies	IC Full time 21 IC Partial 187 Non-caregivers: 344 Age 75 or over Diagnosis frailty	Psychiatric disorder: 30-item version of the General Health Questionnaire Life satisfaction index A (Neugarten 1961) Interpersonal bonding measure (Wilhelom 1988) Disability asked by questions about cooking, mobility, continence, housework, shopping, dressing, feeding, toileting	Stressor Degree of disability is a significant factor for the psychiatric symptoms. The main determinant of distress in caregivers is the perception that the person being cared for was dominating, critical or trying to change the caregiver Internal resource Caregiver characteristics were not in themselves determinants of caregiver distress Outcome The full-time caregivers reported more psychiatric symptoms and lower life satisfaction

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Laidlaw *et al.* 1999	Cross-sectional	Explore the stress of key caregivers of clients with obsessive compulsive disorders	IC 46 Age 48 (24–77) Length mean 16 years Diagnosis OCD	Caregiver stress Caregiver stress assessment by Falloon Life events by Brown and Harris Stress, Subjective burden and attitude to Continuing Care giving; self-developed one-item global rating scale	Stressor High sources of stress; impact of life events and distress caused by disorder Half of IC had a physical health problem 13% had a mental health disorder 37% had treatment for their physical disorder in last two years and 9% had treatment for their mental health disorder External resources Relatively higher sources of stress; marital relationship and family relationships Outcome Half IC moderate burden Quarter IC severe burden 35% extremely distressed at the idea of continuing their care-giving role
Samele & Manning 2000	Cross-sectional	Examine the material changes to relatives' lives and identify relatives who appeared most vulnerable to burden	IC 40 Age 48 Length over two years Diagnosis; S, AP, D	Burden Compilation of the Social Behaviour Assessment schedule, Camberwell Family Interview, Camberwell High Contact survey The following sections: OB, Pt behaviour, Coping, satisfaction with services	Stressor Pt behaviour, social withdrawal Internal and external resources IC maintains friendships, no change in income, good relationship with pt, manage household disruptions. Coping is combination of emotion- and problem-focused coping concerning the pt's behaviour Outcome Burden corresponds with reduction in leisure activities, impact on psychological well-being and perception of pt behaviour Vulnerable; relatives of male, unemployed, pt with psychosis
Beach *et al.* 2005	Longitudinal	Examine the effects of changes in care-giving involvement on changes in caregiver health-related outcomes in a population-based sample of older persons caring for a disabled spouse	IC 680 Diagnosis population-based health status and risk of cardiovascular diseases	Sociodemographic variables Stressful life events list ADL and IADL Quality of the marital relationship all combined in a self-made list	Stressor Increase in care-giving involvement was related to decreased anxiety and depression Changes in the older physical impairment were related to poorer health-related outcomes Outcome Increases in caregiver stress resulting from the help predict poorer perceived health, increase in health risk behaviour and increase in anxiety and depressive symptoms

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Sisk 2000	Cross-sectional	Is perception of burden related to health-promoting behaviours of caregivers of older	IC 120 Age 61·1 Diagnosis physically or cognitively impaired	Caregiver Burden; The objective burden scale and Subjective Burden Scale (Zarit, Montgomery) Physical health; Seriousness of Illness Rating scale (Simon & West) Length in months Demographic characteristics Health promotion behaviour; Health Promotion Lifestyle Profile	Stressor Higher SB tends to score lower health promotion behaviour. OB did not affect health promotion behaviour
Chappell & Reid 2002	Cross-sectional	Assessing overall quality of life of IC, using a path model where burden is conceptualised as distinct from well-being	IC 243 Age 51·1 (21–85)	Well-being Life Satisfaction Scale, by Michalos Self-esteem, by Rosenberg Scale Background variables ADL, by a self-made list Behavioural problems, self-made list Number of hours care giving Perceived support by Perceived Social Support scale Caregiver burden, by Zarit Caregiver Burden Inventory Summary statement focuses on the overall burden	Stressor Cognitive status, functional dependency and behaviour problems are not directly associated with well-being Internal resources Perceived social support and self-esteem are positively related to well-being Perceived social support and formal service use are directly and positively influenced by less ADL dependency Outcome Well-being is directly affected by perceived social support, burden, self-esteem and hours of informal care. Burden is directly affected by increased behavioural problems, frequency of getting a break, self-esteem and hours of care, not affected by perceived burden
Stroup *et al.* 2002	Cross-sectional	Examine the determinants of burden of family members Two interviews in six months to types of groups (type of mental health service)	IC 129 Age 52 (18–90) Diagnosis FPS	A modified version of the Family Experience Interview Schedule (Tessler &Gamache), combined with some items of the Psychiatric syndrome scale by Struening The focus is on; Objective dimensions: Care and control Subjective dimension Worry	Stressor Predictor of care; coresidence, being the parent and more than one symptom Predictor of control; symptoms associated with increased supervision Outcome The predictors of worry are symptoms and coresidence, where symptoms increase worry and coresidence decreases worry 1

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Magliano *et al.* 2003	Cross-sectional	Explore the social network of C with S in relation to relatives sociodemographic characteristics, pt' clinical variables, family burden and pessimism about the consequences of the disease	IC 709 Age 57 Duration 29·7 Diagnosis S	Clinical status pt; Brief Psychiatric rating Scale (1986) Personal and social functioning pt; The Assessment of Disability Interview(1988) Social contacts and support; The Social Network Questionnaire OB, SB and relatives attitude; The family Problems Questionnaire Causes, treatments of the disease and possible roles of pt; The Family Options Questionnaire	External resources More supportive social network in relatives with lower levels of burden. Practical help in emergencies is more available than psychological support Social network is more compromised in spouses and parents Social contacts and psy support are lower among older relatives, lower education level and by those spending more time with pt Levels of support are lower when pt has more severe symptoms and greater disability Relatives who receive more psy support are report less pessimism about pt future
Pinquart & Sörensen 2003	Meta-analyse	Statistically integrate results on the association between stressors and uplifts of care giving with CG's psychological health	IC 228 (articles) Age 59·5 Length 53·9 months Diagnosis D, Cancer, Parkinson	CG burden – CG depression Influence moderator variables	Stressor CG burden – CG depression: CR receiver behavioural problems, fewer perceived uplifts, care-giving hours/ week, long duration Resources Physical impairments Number of tasks Perceived uplifts Stronger associations in probability samples than in convenience samples
Martire *et al.* 2004		Examine the linkages between caregiver factors and pt illness characteristics	IC 12 Age 53·4	Depressive symptoms pt: Hamilton Rating scale for depression Diagnosed with another psychiatric illness and whether or not adhered to pharmacotherapy Burden: The Burden Interview Satisfaction with the relationship Rating on a scale 1–7	Stressor Depressive pt correlate with depressive informal caregiver More depression in informal caregivers corresponds with less relationship satisfaction and pt non-adherence is related to greater caregiver burden Outcome Moderate levels of burden and relationship satisfaction and a high level of rewards from providing care

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Angermeyer *et al.* 2006	Cross-sectional	To investigate the quality of life of spouses of people with S, D, AD and compare with the general population	IC 133 Age 46·9 Length 10·9 Diagnosis S, D, AD	Quality of life WHOQOL, self-administered questionnaire by WHO Functional impairment GAF	Stressor Sign. association of functional level pt and quality of life, psychological well-being and social relationship Outcome No difference between the overall quality of life spouses and general population, however with regard to psychological well-being and social relationships it was lower regardless of the type of illness Physical well-being and environment are not affected
Murray-Swank *et al.* 2006	Cross-sectional	Characterise the nature of religious and spiritual support received by IC with serious mental illness and test hypotheses are adjusted to C adjustment	IC 83 Age 52·2 Length Diagnosis S, MAD	Religiosity and spiritual support; self-developed semi-structured interview Depression, self-esteem, Mastery; modified version of Center of Epidemiologic studies Depression scale and from the Family Impact Survey from Pearlin SB; Family Experience Interview Schedule Self-care; six-item self-care measure by Burland	Internal resources Religiosity is associated with greater self-esteem – self-care and less depression Religiosity not related to SB Religiosity support mastery
Rose *et al.* 2006	Cross-sectional Quantitative/ qualitative	Explore the family caregiver perspectives on needs and concerns for which assistance is desired to fulfil the care-giving role	IC 30 Age 28–76 Length Diagnosis S, BPD, MD	Burden; Burden assessment scale Mastery; sense of Mastery scale Care-giving contexts; severity, contacts with health prof., IC of well they manage the situation Areas of concern; Family Concerns Inventory Pt level of functioning; satisfaction with overall level of functioning Also narrative data	Stressor Relatives feel ill-equipped to recognise and manage illness symptoms Negative symptoms are more bothersome than positive symptoms Perception of severity is related to permanent losses and concerns about the future and isolation Internal resources Mastery scale does not measure the specific situation Support and instruction on how to live on a daily basis is needed Outcome Burden is not related to number hospitalisations

Table 1 (Continued)

Study	Design	Research question	Sample	Variables	Results
Östman 2007	Cross-sectional	Investigate different aspects of Family Burden, need for support and participation in actual care situation with relatives living apart and together with pt	IC 162 Age 43 (19–69) Length = at least 10 years Diagnosis = S, SAD, MD, others	Self-developed questionnaire	Stressor Support daily basis Physical violence Worries self-harm and suicide Internal resource Appraising the care situation negatively Outcome Give up leisure time, work, social isolation, impairment of the relationship, mental health problems of their own., coresidence result in more help and negative appraisal, more social isolation Wishing they never met the pt or never been born

IC, informal caregiver; C, care giving; CR, care receiver; FM, family member; P, professional; FP, functional psychotic; OB, objective burden; SB, subjective burden; CB, caregiver burden; FB, family burden; CB, caregiver burden; MI, mental illness; S, schizophrenia; SAD, schizoaffective disorder; BD, bipolar disorder; D, depression; MD, major depression; MD, mood disorder; AD, anxiety disorder; F, frailty; P/NSB, positive or negative symptom behaviour; PD, physical disease; PDD, pervasive developmental disorder; ADL, activities of daily living.

Results

The final search resulted in 689 articles. After exclusion based on the inclusion and exclusion criteria, 51 articles remained. A flow diagram reflects the search strategy (Fig. 1).

The components of the conceptual model

All retrieved articles were evaluated, and significant effects or associations with perceived burden were subsequently described within the three major components of the stress-theoretical model of Lazarus and Folkman (1984) (Fig. 2). The first component reflects the origins of perceived burden and can be considered to be the actual sources of stress in the care-giving situation. The second component describes the process of appraisal, i.e. the buffering of the effects of stressors. The third component reflects information on the various outcomes, such as perceived burden and the health consequences.

Situation

Concerning the care-giving situation, caregivers experience three major sources of stress: (1) the ongoing problematic behaviour, (2) the care-giving tasks they perform for which they are not prepared, and (3) the losses they experience, such as loss of self (loss of one's identity), loss of a beloved person and loss of opportunities.

Problematic behaviour

Changes in clients' behaviour and mood and the frequency and severity of problematic behaviour are consistently reported to be one of the most important predictors of perceived burden (Thompson & Doll 1982, Noh & Turner 1987, Solomon & Draine 1995, Magliano *et al.* 1996, Buck *et al.* 1997, Stroup *et al.* 2002, Hunt 2003, Ohaeri 2003, Pinquart & Sörensen 2003). Informal caregivers feel more bothered by negative symptoms and passive behaviour (social withdrawal, apathy, slowness, helplessness, hopelessness, impaired cognition and decision-making) than by positive symptoms (Rose *et al.* 2006). The former are seen as a lack of motivation and are therefore, more often considered as a sign of uncooperativeness rather than as a consequence of the mental illness (Pearson *et al.* 1988, Magliano *et al.* 1995, Provencher & Mueser 1997). Positive symptoms like openly annoying behaviour, verbal agitation, suspicion, hallucinations and delusions can be perceived as odd or bizarre and sometimes frightening, but they are obviously linked with the disease and therefore seem more acceptable (Fadden *et al.* 1987, Gubman & Tessler 1987, Noh & Turner 1987, Buck

Table 2 Overview qualitative research

Study	Design	Research question	Sample	Themes	Results
Jeon & Madjar 1998	Phenomenological study	Explore the experiences of daily life to develop a deeper understanding of these experiences	IC 14 Age 37–79 Length six months–36 years Diagnoses S, D, BD	What is it like?	Internal resource Taking each day as it comes, no long-term plans Looking at the World through the eyes of the other, the connection of caregiver and for the person receiving care
Rose 1998a,b	Based on the theory of symbolic interactionism	Increase understanding of the meaning of care giving that caregivers derived from ongoing interactions with the ill relative	IC 15	Focus on the process of how meaning was developed in the context of reciprocal relating between caregiver and care receiver	Internal resource Staying connected. Finding the essence of the person obscured by the mental illness Finding a place for self in influencing the illness Helping the relative to move forward
Chambers *et al.* 2001	Qualitative approach	Explore the emotional support needs and coping strategies of family caregivers	IC 14 Diagnosis PD	IC Needs	Stressor Strong emotional bonds, in-depth knowledge of the client, can mean the caregiver never gets a break Internal resource Coping strategy: Developed a wide range of strategies; acceptance, practical action, simple behavioural interventions External resource Information and training to provide reassurance that one is doing the right thing, information about services, finances, respite care Outcome Loneliness and isolation Frustration associated with inconsistent and irregular support and lack of information
Muhlbauer 2002	Symbolic interaction	Examine the process holistically Search for patterns in the experience	IC 26 Age 56 (40–76) Length over one year Diagnosis S, MD, BD, OCD	Information about mentally ill family member Focus on the phase or stage like development of the experience as a whole	Internal resource: Development of awareness, crises, instability, recurrent crisis, movement towards stability, continuum of stability, growth and advocacy
Rose *et al.* 2002	Grounded theory Longitudinal	Develop theory about managing the experience of being IC, influencing factors regarding that process and identify points in the process where they are in need of help in coping with the illness	IC 29 from 17 families Age 18–73 Length minus two years Diagnosis S, BD, MD	Family's stories of the illness and its start Care-giving role Social and cultural issues Thoughts about the future	Stressor Sense of loss Achievement of normative goals, emotional consequences and a process of ambiguity of illness, seeking control over the illness, adopting possibilities and realities

Table 2 (Continued)

Study	Design	Research question	Sample	Themes	Results
Veltman *et al.* 2002	Qualitative	Greater knowledge of the meaning IC derive from situation, including positive aspects of CG	IC 20 Age 24–73 Length 2–38 years Diagnosis = S, SAD, BD, MD	IC demographic questions CR demographic questions Positive and negative aspects of care giving	Stressor Stigma of illness and care-giving role, resulting in a sense of isolation Internal resource Hope for better admiration and respect for the person struggling with a mental illness. Personal gain External resource Fighting the system asking for support and sharing of the responsibility Financial strains Adequate and appropriate housing
Jones & David 2004	Phenomenological	Examine the experience, in terms of a complex loss, of people who have a family member who suffers from serious mental illness	IC 47 Diagnosis S, BAD	Analysis that was an integration of experiences in the interviews, shaped by reflection, reading and discussion between interviews	Stressor A mentally ill family member is a great change that has been experienced as an never-ending loss Chronic grief while the person is still around Feelings of isolation and anger because others do not understand her feelings Shame is extremely relevant, the impact of the stigma make people reluctant to talk about the person with the illness
Jungbauer *et al.* 2004	Three assessment times in one year	Explore the burdens of spouses of people with schizophrenia	IC 48 Age 22–72 Length Diagnosis S	Changed situation Representations of extreme burden	Stressor Take over additional duties and role changes Passive life is burdensome for the IC Partners separate because of the burden in case of aggression Joint sexuality is spoiled Internal resources With growing experience and better information, the partners' abilities to cope with the problems increase Partners with S themselves are not burdened Outcome Pt illness curve and spouses' experience of burden confirm a close relation Loss of contacts

Table 2 (Continued)

Study	Design	Research question	Sample	Themes	Results
Hallam 2007	Descriptive	Explore how involuntary commitment impacts the family	IC 13	Set of five questions: Has the use of involuntary commitment created benefits for the FM Has the use of involuntary commitment created pitfalls or areas of concern for the FM Are you happy with the type of information and involvement that may change your experienced burden Has the use of involuntary support altered the support you receive Has the use of involuntary support changed your experienced burden	Stressor Difficulties in accessing involuntary commitment placing IC at risk in their homes Personality disorders seems to lead to a negative change in the treatment External resource IC have no rights, not involved in decisions despite the impact it had on on them Insufficient support from health professionals Need for respite care, information and education especially to manage difficult behaviour Hospitalisation is respite and relief is expressed because responsibility for the welfare of the ill person is shared with mental health professional Need for case management
Wynaden 2007	Grounded theory study	Exploring the experience of care giving from the IC perspective	IC 27 Age 31–85 Length 1–33 years Diagnosis S, BD, D	Constant comparative method	Stressor Being consumed, disruption of established lifestyle sustained threat to self-equilibrium, Internal resources Process of seeking balance; trying to make sense of things, restoring self-identity, reaching out to make a difference

IC, informal caregiver; C, care giving; CR, care receiver; FM, family member; P, professional; OB, objective burden; SB, subjective burden, is caregiver burden; CB, caregiver burden; S, schizophrenia; SAD, schizoaffective disorder; BD, bipolar disorder; D, depression; MD, major depression.

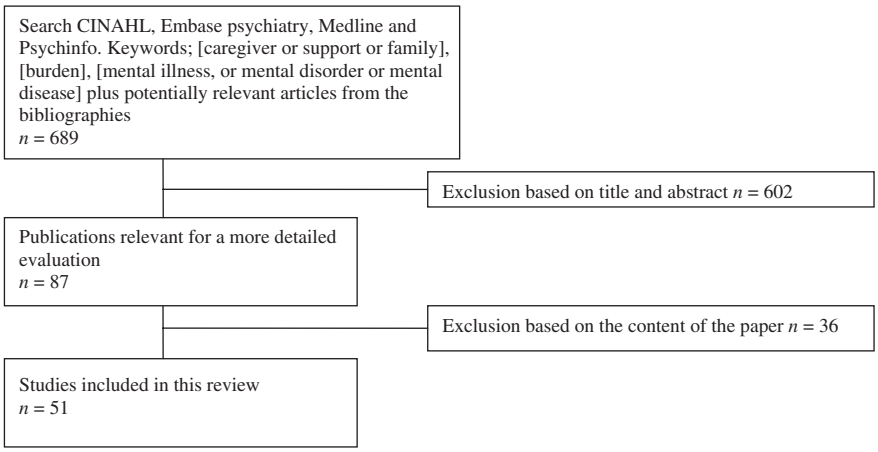

Figure 1 Search strategy.

et al. 1997, Chappell & Reid 2002, Pinquart & Sörensen 2003).

Care-giving tasks

The degree of (social) disability, the severity of symptoms, the uncertainty and unpredictability of the course of the illness (Biegel & Schulz 1999) and complications and crises (Duijnstee *et al.* 2001) are directly related to the kind and number of tasks the caregiver is required to undertake (Montgomery *et al.* 1985, Skaff & Pearlin 1992, Solomon & Draine 1995, Pearson *et al.* 1988, Magliano *et al.* 1996, Chappell & Reid 2002, Pinquart & Sörensen 2003). Over the course of time, the number of tasks increases because of the frailty and (somatic) comorbidity commonly seen in these patients (Montgomery *et al.* 1985, Magliano *et al.* 1996, Sisk 2000). Because of the prevalence of acute and chronic illnesses such as chronic obstructive pulmonary disease (COPD), diabetes, hypertension, heart disease, stroke and the adverse effects of medication use, there is an increase in dependency concerning (instrumental) activities of daily living [(I)ADL]. Informal caregivers do not always feel prepared for their (new) roles (Pearson *et al.* 1988, Norbeck *et al.* 1991). They perform personal care tasks such as washing clothes, bathing and helping to get dressed and health care tasks such as giving injections and monitoring medication intake (Patterson *et al.* 1996). Monitoring tasks such as supervision, regular checking of medication, telephone calls and indirect tasks such as locating and coordinating services, often add to household tasks such as cooking, taking the older person out for a walk, providing transportation and management of finances. Informal caregivers who live in the same house as the older person, particularly spouses, are even more involved in care giving and tend to report more role captivity, when compared to other family members or as to those who live apart (Gallagher & Mechanic 1996, Patterson *et al.* 1996, Solomon & Draine 1996, Buck *et al.* 1997, Jungbauer *et al.* 2004).

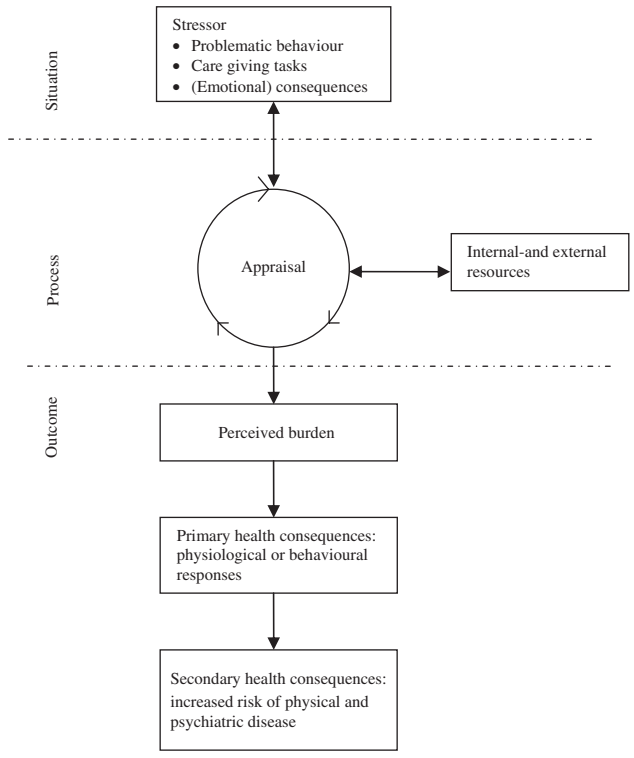

Figure 2 Conceptual model perceived burden adapted from the stress-theoretical model of Lazarus and Folkman (1984).

Emotional consequences

Because of the fact that almost every domain of life is affected by care giving, including employment, social relationships, family relationships and activities, personal interests and hobbies, holidays and finances, it is often impossible to make long-term plans (Jeon & Madjar 1998,

Biegel & Schulz 1999, Angermeyer *et al.* 2006, Rose *et al.* 2006). Informal caregivers manage to cope by taking each day as it comes and not to look too far to the future. Because of this focus on everyday life and the widespread misunderstanding that psychiatric disorders will disappear over time, family and friends may become impatient or tired and leave the social network. In combination with the still existing social stigma, informal caregivers easily become isolated. To prevent a loss of interaction with the broader community, informal caregivers, in particular spouses and full-time informal caregivers, spend a lot of energy on maintaining family and social relationships. They are the only link between the older person and the outside world, including the health care system (Patterson *et al.* 1996, Broe *et al.* 1999, Veltman *et al.* 2002).

Caregivers often feel overwhelmed by the impact of the experience of care giving and of major disruptions in their established life style and their life goals and dreams. They are also overwhelmed by disruptions in their relationship with the ill person and their own emotional responses when confronted with, for instance, difficult behaviour (Jeon & Madjar 1998, Rose *et al.* 2002, Wynaden 2007). In addition, recipients of care may be unsympathetic and often heavily absorbed in their own problems. They hardly ever express gratitude. Therefore, informal caregivers need to keep their expectations low with respect to reciprocity (Östman 2007).

Many informal caregivers experience a profound sense of loss and feelings of grief when a beloved person becomes mentally ill. The adjustment to this loss obviously differs from loss because of death, but the response of informal caregivers to the loss may be similar to the grief response to death (Solomon & Draine 1996). While the ill person is still present in the life of the informal caregivers, such perceived (non-death) losses, contribute to an unending chronic sorrow, as the illness is woven into the lives of informal caregivers on a continuous basis (Karp & Tanarugsachock 2000, Jones & David 2004). This prominence of chronic sorrow, together with grief, anger, frustration, guilt and mourning, is an additional stressor in the informal care-giving experience and is often unrecognised by professionals (Patterson *et al.* 1996, Chambers *et al.* 2001, Rose *et al.* 2002, Jones & David 2004).

Process

The degree of perceived burden is explained by the way the appraisal of the stressors is transformed by the use and the availability of internal and external resources (Pearlin *et al.* 1981, Solomon & Draine 1995). Informal caregivers 'seek balance': they try to make sense of what is happening and try to restore their self-identity (Wynaden 2007).

Internal resources

Personality. Personality has been hypothesised to affect the appraisal process. The results of the Hooker *et al.* (1992) suggest that to understand the process fully, the personality of the caregiver must be taken into consideration. In this study, neuroticism and optimism are both significantly related to mental and physical health outcomes. Informal caregivers who have high neuroticism scores, rate themselves as more stressed and as less physically healthy. They have more depressive symptoms and lower psychological well-being. They also report more chronic conditions diagnosed by a doctor. Informal caregivers who score high on a scale of optimism, rate themselves as less stressed, have fewer symptoms of depression and have higher levels of psychological well-being.

Coping style. Coping skills are often cited as an important personal resource. An informal caregiver needs skills to manage strong emotions as well as difficult and often challenging situations (Hill *et al.* 1998, Jeon & Madjar 1998). With a problem-focused coping style, informal caregivers handle difficult situations in a more satisfying manner and this increases their confidence (Noh & Turner 1987, Solomon & Draine 1995, Hill *et al.* 1998, Magliano *et al.* 1999, 2003, Chappell & Reid 2002, Martire *et al.* 2004). A more emotion-focused coping style is more often seen in situations where the older client seems to take no responsibility for his or her own actions (Magliano *et al.* 1995, 1999). In those situations, the caregiver uses coercion, resignation and avoidance (Magliano *et al.* 1995). Researchers have also discovered that, in times of adversity, some informal caregivers demonstrate an unusual level of competence. This evidence of resilience (Mannion 1996, Marsh *et al.* 1996) makes it imperative to include resilience in the conception of the experience of informal caregivers. Informal caregivers feel relief if the responsibility for the welfare of the older person with a mental illness can be shared not only with other family members or friends but also with a mental health professional who is familiar with the situation (Hallam 2007).

Self-concept. Informal caregivers report positive and negative changes in self-esteem and self-confidence (Hill *et al.* 1998). The informal caregivers who are able to accomplish future goals, maintain a variety of interpersonal relationships and sustain a sense of identity, experience competence and power (Rose 1998a,b). They find their role more fulfilling and uplifting (Veltman *et al.* 2002). They do experience

burden, but they learn new things that give them an awareness of inner strength and growth as a human being. Informal caregivers who are more confident are more successful in handling difficult situations. They experience fewer ups and downs in their self-esteem and perceive less burden (Noh & Turner 1987, Skaff & Pearlin 1992, Solomon & Draine 1995, Patterson *et al.* 1996, Hill *et al.* 1998, Hunt 2003, Pinquart & Sörensen 2003). In his study, Murray-Swank *et al.* (2006) found that a substantial proportion of informal caregivers mobilise religious and spiritual resources to cope with their situation and experience greater self-esteem and self-care and less depression. In their opinion, religion is supportive to mastery.

Mastery is defined as a general measure of confidence. Self-efficacy measures the situation-specific perception of skills (Maibach & Murphy 1995, Solomon & Draine 1995). The mastery scale (Pearlin *et al.* 1981) appears not to be an accurate measure of the lack of control informal caregivers feel in specific illness-related situations (Rose *et al.* 2006). Thus, the results of measuring differ according to the instrument used. For instance, the informal caregivers in the study of Solomon and Draine (1995) judge their knowledge and the situation-specific skills as insufficient, despite their overall confidence in handling difficult situations in general.

External resources

Diverse activities. Informal caregivers who maintain some form of employment express less distress because work provides a distraction from the impact of the illness (Hallam 2007). Relatives who are forced to give up leisure activities or their occupation have fewer sources of positive feedback. These sources of feedback prevent caregivers from being overwhelmed by their situation (Skaff & Pearlin 1992, Östman 2007). However, some activities can also be experienced as a burden (Buck *et al.* 1997).

Skills. Older clients who suffer functional deficits and somatic comorbidities are often in need of assistance with ADL (e.g. bathing) and IADL (e.g. handling money). After the age of 65, somatic comorbidities may gradually exacerbate pre-existing problematic behaviour. Mental illness, problematic behaviour, frailty and other complaints accompanying ageing are interrelated. However, with growing experience and better information, the coping abilities of informal caregivers increase (Jungbauer *et al.* 2004).

Social support. Social participation, instrumental support and emotional support all help to reduce stress (Noh & Avison 1988, Solomon & Draine 1995, Cuijpers 1999, Chambers *et al.* 2001). Informal caregivers who exploit their network of social support show a more accepting style in handling problems (Norbeck *et al.* 1991). Informal caregivers look for a person who understands their feelings (Jeon & Madjar 1998), supports their thoughts and ideas (Solomon & Draine 1995), someone in the immediate circle with whom they can talk freely, without fear or stigmatisation. This affirming support contributes to adaptive coping.

In situations where the older person has a social network of his or her own, the informal caregiver is even more optimistic about assisting the care receiver (Birchwood & Cochrane 1990, Magliano *et al.* 1995, 2003). When family, friends or neighbours are together involved in care giving, however, different ideas about how to handle the situation may make things more complicated (Cuijpers 1999, Chappell & Reid 2002). From the life course perspective, loss of friends and family through death or physical decline can lead to a shrinking social network, which in turn can exacerbate feelings of loneliness and social isolation (Patterson *et al.* 1996).

Outcome

The literature related to outcome shows that if there is no balance between the actual situation and the use of internal and external resources, perceived burden and primary and/or secondary health consequences will become apparent.

Perceived burden

Perceived burden is the result of various diverse and interrelated determinants and is therefore seen as a complex process (Lazarus & Folkman 1984, Pearlin *et al.* 1981, Schene 1990, Patterson *et al.* 1996, Greenberg *et al.* 1997, Biegel & Schulz 1999, Stam & Cuijpers 1999). Although adequate coping mechanisms will reduce stress, a certain amount of burden will remain. A high amount of perceived burden increases the risk of negative physical, psychological and physiological outcomes. Therefore, negative outcomes with regard to physical and mental health and well-being are a potential sign of a high level of perceived burden (Thompson & Doll 1982, Noh & Turner 1987).

Health consequences

The literature results can be distinguished into two different types of health consequences. In this review, they are described as 'primary health consequences' and 'secondary health consequences'. The primary health consequences are mainly psychosocial or behavioural responses to a high level

of perceived burden. Secondary consequences, on the other hand, are the more objective consequences that cause damage to the physical and mental health and well-being of the informal care giver.

Primary health consequences

Physiological, behavioural and emotional responses such as lack of sleep, anger, irritation, headache, worry, guilt, discouragement and a poor diet (Thompson & Doll 1982, Montgomery *et al.* 1985, Magliano *et al.* 1996, 1999, Provencher & Mueser 1997, Samele & Manning 2000, Stroup *et al.* 2002) are often seen. These complaints may lead to exhaustion or fatigue and feelings of hopelessness and powerlessness (Magliano *et al.* 1995, Gallagher & Mechanic 1996, Patterson *et al.* 1996, Jeon & Madjar 1998, Laidlaw *et al.* 1999, Sisk 2000, Hunt 2003), resulting in a higher amount of perceived burden and a failure to address one's own health problems. Compared with the general population, the overall quality of life of caregivers of spouses appears to be lower (Angermeyer *et al.* 2006). Informal caregivers, in general, show an increased use of (self) medication and less visits to their general practitioner (Pruncho & Potashnik 1989).

Secondary health consequences

Secondary health consequences are the objectively attributable physical, psychological, social and financial consequences to the care-giving situation (Patterson *et al.* 1996, Chappell & Reid 2002). Compared with a group of similar aged non-caregivers, informal caregivers are at greater risk of physical and psychiatric diseases such as cardiovascular diseases, infectious diseases because of decreased cellular immunity, weight change and clinical depression (Pruncho & Potashnik 1989, Patterson *et al.* 1996, Duzijn *et al.* 2000, Beach *et al.* 2005). They report higher rates of diabetes, arthritis, ulcers and anaemia. It has been suggested that more than half of the informal caregivers need medical attention because of these secondary consequences (Fredman & Daly 1997, Laidlaw *et al.* 1999).

Discussion

The present study has brought together the scattered and partial explanations of the origins of perceived burden and organised these in a process-oriented conceptual model adapted from the work of Lazarus and Folkman (1984). This model indicates that perceived burden is the outcome of a complex interplay between stressors and internal and external factors that buffer the negative effects of the stressors. So far, research on the origins of perceived burden mainly focused on static relations. This study stresses the importance to take into account the dynamics, the circularity of the process and the interrelatedness of these relations in the design of intervention strategies to reduce caregiver burden and argues that this strategy is likely to be more effective than interventions that focus on one, or just a limited amount of potential causes of perceived burden.

In choosing a proper intervention, nurses need to know the caregivers perception of the care-giving situation. Nurses have the opportunity to attain this knowledge because they have access to the private world of the caregiver. By developing intimate relationships with the caregivers, nurses may encourage caregivers to indicate their perceived burden so they can advice on how to handle, for instance, the apparently never-ending unpredictability of behavioural problems. As nurses participate in the care-giving system, they can observe caregivers' coping style and the amount of social support given to the care recipient. Informal caregivers express their feelings of grief and sadness about caring for an older person who is not getting better. In sum, the nurse is in a unique position to tailor an intervention that naturally fits the situation. Their support is easily accessible because of the frequency with which they meet the patient and his or her informal caregiver.

Although the (community) mental health care nurses are in a unique position to support informal caregivers of older patients with severe mental illness, a complex, multivariate intervention that is comprehensive, long-term, individually tailored and has the flexibility to meet the dynamics of burden over time, is not yet available.

Conclusion

Based on the literature, we may conclude that perceived burden must be seen as the result of a complex interplay between a variety of factors. This suggests that further research or clinical practice should take into account this complexity of perceived burden especially in a situation where the mental illness is chronic and probably unsolvable. The focus on a single cause might not be effective in reducing perceived burden in the long term. This overview of the most important sources of burden helps to develop a complex, multivariate intervention that is comprehensive, long-term, individually tailored and has the flexibility to meet the dynamics of care giving over time. With this intervention, the mental health care nurse can support the often aged partners, children or siblings of these older persons with a severe functional psychiatric syndrome and concomitant problematic behaviour.

Relevance to clinical practice

Knowledge about the origins of perceived burden is important for structuring nursing clinical expertise and designing effective strategies to support the informal caregivers of older people with a severe functional psychiatric syndrome and concomitant problematic behaviour to improve their quality of life. The conceptual model can be used as a guidance in assessing and organising the appropriate information needed to support the informal caregiver in a structured way.

Contributions

Study design: MZ, MG, PC; data collection and analysis: MZ, MA, MG and manuscript preparation: MZ, MA.

Conflict of interest

No conflict of interest.

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